FAIRVIEW
Fairview-University Medical Center

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Commissioner of Social Security
PO Box 17703
Baltimore, Maryland 21235-7703

Dear Commissioner:

We submit that the new proposed Listing of Impairments for hemophilia and von Willebrand disorder needs to be reevaluated and modified. Specifically, the issues which are of concern are as follows:

7.03B. and **107.03B. Hemophilia** with **spontaneous** bleeding despite **prophylactic** factor **replacement**, occurring at least 3 times in a consecutive 12 month period.

Comment #1: Prophylaxis is not the universal standard of *care.* Many adults with severe hemophilia are not on prophylaxis. Prophylaxis *is* considered to be optimal therapy for children with severe hemophilia, to prevent joint damage and long term disability. However, data collected from the Centers for Disease Control and Prevention indicate that 44% of individuals with severe hemophilia under the *age* of 18, and 85.5% of patients over the age of 18 are not on prophylaxis. *An* even greater number of people with moderate hemophilia (>1% factor VIII or FIX) *are* not on prophylaxis. Therefore, a very significant number of people are on "demand therapy" (treatment of bleeding episodes only at the time of the bleed) and not prophylaxis. Based on the data, we recommend removing the prophylaxis clause from the Listings.

Comment #2: Regarding the joint deformity requirement section of the listing for children, individuals with hemophilia have a different type of joint disease than those with juvenile rheumatoid arthritis. Hemophilia related joint disease *is* the result of repeated bleeds. Therefore, they need to be listed separately. Alternatively, we urge you *to* consider whether a listing in this section is necessary, given that joint bleeds and subsequent arthritic disease are considered to be a complication of hemophilia.

Proposed 113.21E. How Do We Evaluate Episodic Hematological Disorders?

"...In every listing in which we require more than one event (bleeding episode), there must be at least one month between the events (bleeding episodes), in order to ensure that we are evaluating separate episodes."

Comment: People with bleeding disorders may have many separate spontaneous bleeds at various sites occurring during a one month period. Alternatively, an individual could have several separate bleeding episodes in the same muscle or joint during the same month. Therefore, we think this rule needs to be changed.

7.03 and 107.03C. **Other hypocoagulable** states (such as **von** Willebrand disorder or **thrombocytasthenia)** with **spontaneous** bleeding requiring hospitalization (for 24 hours **or** mow), occurring at **least** 3 **times** in a consecutive 12 month period.

Comment: Individuals with von Willebrand disorder do not regularly require hospitalization to control bleeding episodes, we recommend they not be *separated* from hemophilia in the new Listings. We recommend the removal of the hospitalization requirement clause.

Sincerely yours, Margaret Heisel

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